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An exploratory study was conducted to obtain information regarding staff requirements in small tumor registry centers, involving a brief analysis of existing tumor registry centers and exploration of training and organizational factors that might be associated with establishing new centers. Activities performed by tumor registry personnel were defined as: (1) selecting medical records for registry purposes. (2) abstracting records, (3) coding records for data processing purposes, (4) initiating follow-up for cases within the registry, (5) maintaining registry files, (6) preparing reports, (7) activating a registry, and (8) supervising personnel and operations. It was found that various kinds of guidance and reference materials did exist for the eight activities but there were no formal training programs and there was a need for improving existing materials. The development of a self-instructional package for teaching medical terminology appeared to be particularly desirable. Study findings are discussed under the headings: (1) objectives, services, and procedures for a state-wide tumor registry system, (2) centralization of activities, (3) alternative systems, (4) relation between procedural alternatives and physician involvement in record abstracting, (5) training implications, and (6) research projects. (JK)

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HumRRO Division No. 1 (System Operations)

VT008150

HumRRO

The George Washington University
HUMAN RESOURCES RESEARCH OFFICE

January 1969

Prepared for:

Louisiana Regional Medical Program

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Prepared for:

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HumRRO Division No. 1
(System Operations)
Alexandria, Virginia

The George Washington University
HUMAN RESOURCES RESEARCH OFFICE

Technical Report 69-101

The Human Resources Research Office is a nongovernmental agency of The George Washington University, established to conduct research in the field of training and education. HumRRO's general purpose is to improve human performance, particularly in organizational settings, through behavioral and social science research, development, and consultation.

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Abstract

An exploratory study to obtain information bearing on the job and staff requirements that might exist at small Tumor Registry Centers was conducted by the Human Resources Research Office (HumRRO) under the sponsorship of the Louisiana Regional Medical Program (RMP). The study involved a brief analysis of existing Tumor Registry Centers and exploration of training and organizational factors that might be associated with establishing new centers. The development of a self-instructional training package for teaching the medical vocabulary required of a Tumor Registry secretary was recommended. Study findings were discussed under the following headings: the objectives, services, and procedures for a state-wide tumor registry system; centralization of tumor registry activities; alternative tumor registry systems; relation between tumor registry procedural alternatives and extent of physician involvement in record abstracting; training implications of a state-wide tumor registry system; and research projects relating to Tumor Registries.

Descriptors

Tumor Registry
Tumor Registry Secretary
Medical Vocabulary
Training
Self-instruction
Medical Records
Abstracting
Coding
Medical Records Librarian
Louisiana Regional Medical Program

Acknowledgment

The HumRRO representatives for this activity, Dr. C. Dennis Fink and Dr. Herbert B. Leedy, wish to express their appreciation to the many people who provided invaluable assistance and information during the conduct of this study. These persons include: Dr. Sabatier, and members of his staff of the Louisiana Regional Medical Program, Dr. Ryan, Miss Robertson, Mrs. Wogan, and the Medical Records librarians and Tumor Registry secretaries who were interviewed during the conduct of this study.

FOREWORD

In cooperation with Dr. Robert Ryan, Department of Surgery, Tulane University School of Medicine, the Human Resources Research Office (HumRRO) of The George Washington University, in the spring of 1968, prepared a research proposal on training Tumor Registry abstractor/coders. This proposal was submitted to the Louisiana Regional Medical Program (RMP). After review, it was agreed that the proposal would be expanded to emphasize the training of supervisory-level personnel who would be responsible for establishing and operating Tumor Registry Centers in small and medium-sized hospitals. Interest in this aspect of training derived from the desire of the RMP to establish a state-wide network of Tumor Registry Centers within the state of Louisiana.

To obtain information that would bear on the job and staff requirements which might exist at small Tumor Registry Centers, it was decided that HumRRO would conduct a brief exploratory study before proceeding with modification of the research proposal. The study involved a brief analysis of existing Tumor Registry Centers and exploration of training and organizational problems that might be associated with establishing new centers.

The study was conducted during the week of 21 July 1968, under the sponsorship of the Louisiana Regional Medical Program. Dr. C. Dennis Fink, HumRRO Senior Staff Scientist, was the principal investigator. Assistance was provided by Dr. Herbert B. Leedy, HumRRO Research Scientist.

The study was conducted and the initial draft of the report prepared in the following assumed context: (a) the state of Louisiana intended to establish a state-wide network of Tumor Registries; (b) the objectives and characteristics of this proposed state-wide registry system would be defined by the state's Tumor Registry planning subcommittee; (c) the abstracting and coding procedures of the End Results Group of the National Cancer Institute (NIH), now followed at the Charity Hospital (New Orleans), were one set of procedures that would be considered for adoption on a state-wide basis. These were the conditions as they existed prior to 5 August 1968.

On 5 August 1968, at a meeting of representatives of the American College of Surgeons, American Cancer Society, Regional Medical Program, End Results Group, and many other medical groups, a proposal for the establishment of service-oriented Tumor Registries throughout the nation was accepted in principle. Under this proposal, abstracted data from local Tumor Registries would be fed into a central data-processing facility which would be capable of providing a variety of reports to the local hospital. An associated meeting of the American College of

Surgeons adopted the position that hospitals should have a Tumor Registry as a service function, and not as merely a disease list.

While many aspects of the program remain to be worked out, the decision to emphasize the establishment of Tumor Registries on a nation-wide basis obviously has far-reaching staffing and training implications. The new ACS-RMP policies will change the context in which the findings and implications of the HumRRO exploratory study will need to be examined. After consideration of advantages and disadvantages, the researchers decided not to alter the content of the body of the report that had already been prepared; it is believed that the material as originally collected and viewed should provide information that would be useful to those considering actions to be taken in relation to the new Tumor Registry program, and that the findings and implications as originally stated can be re-interpreted with reference to new conditions and needs. As a beginning to such a re-examination, an Addendum has been provided for this report, giving some additional information on the ACS-RMP actions of August 5 and appending a copy of the DRMP position paper on registries, and discussing some of the effects that could be expected from abstracting and coding procedures that might now be required of Tumor Registries.

In view of the changing circumstances, it seems evident that the planned revision of the Dr. Ryan-HumRRO proposal on training of Tumor Registry abstractor/coders should be deferred until the nature of the Louisiana State Tumor Registry System is more clearly defined. However, there are other aspects of pertinent research -- for example, development of a self-instructional training package for teaching the medical vocabulary required of a Tumor Registry secretary -- that could proceed while the registry system definition is under way.

August 1968

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Staffing and Training Requirements for Tumor Registry Centers in the State of Louisiana

Section I

SUMMARY AND IMPLICATIONS OF THE STUDY

Purpose of the Study

An exploratory study to obtain information bearing on the job and staff requirements that might exist at small Tumor Registry Centers was conducted by the Human Resources Research Office (HumRRO) under the sponsorship of the Louisiana Regional Medical Program (RMP). The study involved a brief analysis of existing Tumor Registry Centers and exploration of training and organizational factors that might be associated with establishing new centers.

Prior to this study, in cooperation with Dr. Robert Ryan of the Tulane University School of Medicine, HumRRO had prepared a research proposal to the Louisiana RMP on the training of Tumor Registry abstractor/coders. Because the RMP was interested in establishing a state-wide network of Tumor Registry Centers, it was agreed that the HumRRO proposal would be expanded to emphasize the training of supervisory-level personnel who would be responsible for establishing and operating Registries in small and medium-sized hospitals. The exploratory study reported here was performed to provide basic information for general planning purposes, as well as for use in revising the research proposal.

Procedures

During the week of 21 July 1968, two HumRRO research staff members carried out the following activities: (a) reviewed in detail the activities of Tumor Registry personnel at the Charity Hospital (New Orleans) Tumor Registry Center; (b) interviewed the Medical Records librarian and the Tumor Registry secretary at five small to medium-sized hospitals in the New Orleans and Baton Rouge areas; (c) held discussions with the Hospital Tumor Registry consultant and former director of the Tumor Registry Center at Charity Hospital; held discussions with personnel of the Louisiana Regional Medical Program.

Information collected with regard to staffing and organizational factors of existing Tumor Registry Centers is summarized in Section III of this report, following a brief statement in Section II of background and data collection procedures. The remaining sections present general information gathered during the survey, pertinent to the decisions that will need to be made by personnel responsible for establishing and operating the proposed state-wide system. Section IV is a discussion of possible objectives, services, and procedures for a state-wide tumor registry system. Section V describes alternative ways of organizing such a system, and Section VI discusses the relation between procedural alternatives and the extent of physician involvement in record abstracting. Section VII discusses training implications of a state-wide

registry system, and Section VIII briefly notes possible research projects relating to tumor registries in areas other than training. (As noted in the Foreword, an Addendum to the report describes recent actions at a national level that will influence the type of organizational planning to be done for the proposed state-wide system. This occurred after the present study was completed and will affect interpretation of factors noted in the remainder of this section.)

Findings and Implications

1. Information gathered on the existing Tumor Registry centers included the following findings:

a. Within the state of Louisiana, four different types of Tumor Registry Programs are in existence. These programs differ with respect to the complexity of the abstracting and coding procedures associated with each system. At the one extreme is the system employed by Charity Hospital (New Orleans), which is patterned after the End Results Group procedures of NIH, and which requires an average of two hours to abstract and code a single record. At the other extreme is the Info-Dex system, a commercially provided system whose abstracting procedures require about 10-15 minutes per hospital record.

b. No formal training programs exist for the training of Tumor Registry personnel at Charity Hospital (New Orleans); training there essentially consists of a six-month apprenticeship program. No formal training programs are associated with other registries in the state.

c. The desire to establish Tumor Registry Centers at individual hospitals within the state apparently is on the increase, but the extent of this desire is still unknown. At present nine hospitals have indicated their readiness to establish Tumor Registry Centers as soon as state-wide standardized procedures for such registries have been established.

d. A medical record librarian does have the qualifications to supervise the establishment and operation of a Tumor Registry Center. It would appear that they could take on this additional duty if no more than 3-4 hours per week was required.

e. The manner in which members of the hospital staff utilize Tumor Registry information varies widely and seems to be a function of the interest exhibited by the surgery department. The establishment of a registry at any hospital should be coupled with an active user education program.

f. The reliability of Tumor Registry abstractor/coders is highly questionable especially when employing complex procedures, such as those required at the Charity Hospital (New Orleans) Registry or the End Result Group at NIH.

2. The Tumor Registry Planning Subcommittee has just been formed and has not yet had the opportunity to formulate any specific plans for establishing the state-wide Tumor Registry system planned for the state of Louisiana. It is felt that plans for development of a specific

training program for Tumor Registry supervisors and/or abstractor/coders would most usefully be delayed until the objectives and characteristics of the state-wide system, and the job responsibilities that would be entailed, have been more fully defined.

3. The information-gathering activities of the present study served to bring into focus questions in some of the areas with which the Tumor Registry Planning Subcommittee will need to be concerned in determining the nature of the state-wide system. These areas include the following:

a. Purposes of Centers. What purposes or objectives commonly attributed to Tumor Registry Centers should be emphasized in a state-wide system? Should emphasis be given to the collection of epidemiology information or to the collection of information pertaining to local conditions and practices, and what types of information should be collected in support of each of the above?

b. Procedures. What Tumor Registry system abstracting and coding procedures should be adopted state-wide -- the sophisticated Charity Hospital (New Orleans) procedures or something similar to the simplified Info-Dex system? As an alternative, would it be more practical to adopt a dual system approach whereby Charity Hospital Registry procedures would be applied to larger hospitals and a simplified system to the smaller community hospitals?

c. Organization. To what extent should a state-wide Tumor Registry system be centralized? Should each hospital have a complete abstracting/coding capability and a complete data processing and report preparation capability? Can certain capabilities of the Tumor Registry system be centralized at the community level? Should certain types of services (data processing) be centralized at the state level?

d. ERG Relationship. What should be the relationship between the NIH End Result Group and a state-wide system? Should all data collected within the state-wide system be capable of serving as inputs to the End Result Group system, or should certain segments of a state-wide system be capable only of selecting those cases which if desired could be readily selected for intensive study by End Result Group personnel?

e. Standardization. To what degree should the record keeping practices of the hospitals within a state be standardized, both in terms of content and format so as to ease the burden of collecting Tumor Registry data?

f. Staffing. What should be the recommended staffing for large and small Tumor Registry Centers? Should the Medical Records librarian for a small hospital perform all Tumor Registry activities, or should the Tumor Clinic secretary take on these activities? Should the Tumor Registry system organizationally be under the Medical Records Department, or under some other department such as surgery?

Section II

BACKGROUND AND METHODOLOGY

Background

A wide variety of national, state, and local medical agencies and associations are actively interested in the establishment and maintenance of Tumor Registry (TR) Centers. Since 1933 the American College of Surgeons has been actively engaged in the establishment of Tumor Registries. As a more recent national development, the Cancer Chemotherapy National Service Center (CCNSC) of the National Cancer Institute has established an End Result Program under which nine large hospitals and three state Tumor Registry systems are collecting a wide variety of information on the diagnosis and treatment of tumors. The Charity Hospital of New Orleans is a participating member of this End Results program and since 1963 has had a highly sophisticated Tumor Registry Center.

A Tumor Registry Center serves four purposes: (a) help provide quality control in the diagnosis and treatment of tumors; (b) provide procedures for the follow-up of patients to obtain data on detection of treatable diseases and to accumulate time-mortality data for the assay of end results; (c) provide information which can serve an educational purpose; and (d) provide data for research purposes, to include epidemiology research.

The desire to establish state-wide and/or national Tumor Registry systems has been frustrated by the expense of operating a sophisticated system and the lack of training programs for personnel who would be required to operate such systems. Furthermore, the four general purposes of a Tumor Registry Center do not equally apply to all sizes and types of hospitals; hence, a single type of Tumor Registry may not be applicable to all hospitals.

The problem of providing trained personnel of Tumor Registries is receiving increased attention. Within the past year, Dr. Robert Ryan, the technical consultant and general supervisor for the Tumor Registry Center at Charity Hospital, New Orleans, has been asked if he wished to develop a training program for Tumor Registry personnel which would be self-instructional in nature and which could be used nationwide. Within the same time period a decision was made to consider the creation of a state-wide Tumor Registry system within the state of Louisiana.

These two occurrences led to the Louisiana Regional Medical Program's interest in an exploratory study of the training and staffing requirements of the Tumor Registry Centers. The consulting study described herein is an outgrowth of this interest. The scope of this study was (a) to obtain basic data pertaining to job requirements at existing Tumor Registry Centers; (b) to ascertain the training and organizational problems which might be associated with the establishment of large numbers of Tumor Registry Centers; and (c) to examine the feasibility of assigning to the Medical Records librarian the supervision of a Tumor Registry Center at small community hospitals.

Information Collecting Methodology

The findings developed during this study are based on a review of a wide variety of literature, plus interviews with persons associated with Tumor Registries in the state of Louisiana. More specifically, the findings are based on:

1. A review of the literature and reference material on Tumor Registry developed by the American College of Surgeons.

2. A review of the literature and reference material developed by the End Result Group of the Cancer Chemotherapy National Service Center of the National Cancer Institute.

3. A review of the material developed by personnel of the Tumor Registry of the Charity Hospital of Louisiana (New Orleans).

4. A review of material prepared by Mrs. Marion Wogan, Louisiana State Medical Society, hospital Tumor Registry consultant.

5. A brief analysis of the job duties of abstractor/coders at the Charity Hospital Tumor Registry. This was accomplished in cooperation with Miss Brent S. Robertson, director of this registry.

6. Interviews with the Medical Records librarian, and when possible the Tumor Registry secretary, at the following hospitals:

V.A. Hospital, New Orleans
USPH Service Hospital, New Orleans
Touro Infirmary, New Orleans
Lallie Camp Charity Hospital, Independence, La.
Earl Long State Hospital, Baton Rouge

7. Periodic discussions and conferences with J. A. Sabatier, Jr., M.D., Director, Louisiana Regional Program and staff.

8. Discussions with Dr. Robert Ryan, Department of Surgery, Tulane Medical School.

Section III

EXISTING TUMOR REGISTRY SYSTEMS

Existence of Four Different Types of Tumor Registries

Four different Tumor Registry systems, varying widely with respect to abstracting and coding procedures, are being employed within the state of Louisiana.

1. The most complex system used by the Tumor Registry at Charity Hospital (New Orleans), is designed to provide all of the information required by the End Result Group of CCNSC and, in addition, to collect certain information of interest to the staff at Charity Hospital and Tulane Medical School.

From an operational standpoint the outstanding feature of this system is the complicated coding procedures that must be followed in

order to convert abstracted material into a code which meets the requirements of the CCNSC End Result Group. To make the necessary sophisticated coding judgments, a detailed and time-consuming abstracting process must be performed. This total abstracting/coding process requires one and one half to two hours for each case. A fully trained abstractor/coder processes no more than five records per day, on the average; it is doubtful that even this processing rate can be sustained for long periods of time.

No formal training procedures have been developed at Charity Hospital for teaching new persons how to abstract and code records in accordance with these procedures. Instead, an apprenticeship program of approximately six months of on-the-job training is used to train new personnel.

Reference or job aid material has been prepared by both the End Result Group and Charity Hospital Tumor Registry personnel to provide abstracting and coding guidance. However, this material is far from definitive and an abstractor/coder must often use her own judgment. For some cases a medical consultant must be called in before the coding can be completed.

There is informal evidence suggesting that reliability is rather low; that is, qualified abstractor/coders, when individually processing the same records, would come out with different information. This is not surprising, since the complex abstracting/coding procedures require non-medical personnel to make judgments that even medically trained experts probably could not make with a high degree of unanimity.

2. The Veteran's Administration Hospitals in New Orleans and Shreveport employ a Tumor Registry system which is patterned somewhat after that recommended by the American College of Surgeons, but which was developed in the 1950's in conjunction with the American Cancer Society and personnel from the NIH National Cancer Institute. To accompany this system there is a Veteran's Administration training document similar to the material produced by the American College of Surgeons.

The abstracting and coding procedures for this system are relatively simple, and it is estimated that it takes only 15-20 minutes to abstract and to code a single record. The system has no quality control procedures, so the reliability of the coding and abstracting is unknown.

During a five-year period, the Veteran's Administration had an experimental Veteran's Hospital-wide Tumor Registry system for the exchange of information. This hospital-wide system has been discontinued.

3. A third Tumor Registry System, differing only slightly from that suggested by the American College of Surgeons and that used by the VA Hospital, is the one used at Confederate Memorial Medical Center. This is a rather simple system in which only 10-15 minutes is required to abstract and to code a new case.

4. The most widely used Tumor Registry System in Louisiana is the Info-Dex System, which consists of a series of fairly simple forms and is provided in a package form by a private organization. Detailed instructions are provided on how to set up a file system, operate the

system, and follow-up cases. However, no training information on abstracting of cases is provided. Moreover, no coding is required with the system; all information retrieval is by manual means through the use of tabs. From the standpoint of establishing and operating a registry, this system has wide appeal because it comes in a package form, does not require coding of information, and provides a relatively easy way to abstract the information that has to be put on the forms. It is, however, not suitable for the processing, storage, and retrieval of large amounts of data.

What type of Tumor Registry system should be adopted for the state of Louisiana? To establish an adequate state-wide system, a determination will need to be made of which type of Tumor Registry system should be selected, or whether a dual system should be employed in accordance with the size or the type of hospital. If, for example, it were decided to employ state-wide the Charity Hospital (New Orleans) system, a tremendous staffing and training problem would exist; it is doubtful whether, in the smaller hospitals, adequate training could be provided for using these complex abstracting/coding procedures.

The desirability of collecting such complex Tumor information throughout the state is, in fact, unknown. It would appear appropriate to examine the degree to which local and state needs can be met by procedures akin to the more simple Info-Dex procedures. Quite possibly, modification in the Info-Dex abstracting procedures could provide for the collection of information which, although much grosser than that collected for the End Result Group, would still be compatible with the categories of information collected for the End Result Group.

Availability of Training Programs for Tumor Registry Personnel

At present there are no formal training programs associated with the Tumor Registry systems within the state of Louisiana. Various types of references and coding and abstracting instructions have been prepared for these systems, especially for the Charity Hospital (New Orleans) system. However, even in Charity Hospital the training is primarily on-the-job apprenticeship.

Since no training programs exist, no matter what Tumor Registry procedures are adopted within the state, it would be reasonable to begin development of training material with a job analysis of the activities required to implement the adopted system and procedures. Appropriate training material could then be developed. The development of self-instructional packages would also begin with analysis of job positions that would be created within the Tumor Registry System.

This type of job analysis could begin as soon as the nature of the state-wide Tumor Registry System has been determined in enough detail so that the job positions within that system can be fairly accurately described.

Capability of Tumor Registry Personnel at Charity Hospital to Assist in the Development of a Training Package

The Tumor Registry at Charity Hospital (New Orleans) has personnel

who could provide the content expertise required during the development of a training program concerned with teaching the End Result Group abstracting/coding procedures. However, the registry has a two-year backlog of cases to abstract, and will not be able to work off this abstracting load until the abstractor/coders are adequately trained in the new End Result Group procedures. Even then, the personnel strength of this registry is such that they will be hard pressed to keep up with their current abstracting/coding load. It would place an undue burden on this Registry to request that they, without additional personnel support, provide the personnel to conduct and/or assist in the development of training materials for TR personnel.

It would appear that any training project that envisions using Charity Hospital personnel should begin by augmenting the Registry staff for approximately six months by establishing at least one additional job position. In this way the Tumor Registry Director and other persons selected by her could be freed for additional training program development duties without jeopardizing the ongoing activities of the Registry.

Role of Medical Records Librarians in a State-wide Tumor Registry Program

In all hospitals visited that had ongoing Tumor Registries, with the exception of Charity Hospital (New Orleans), the Registry was under the supervision of the Medical Records Librarian. The work of the Registry was often performed by a Tumor Registry Secretary. It seems evident that the Medical Records Librarian does have the qualifications to supervise a Tumor Registry. In very small hospitals, the Librarian probably could add operation of a Registry to her duties if the additional work would require no more than 3-4 hours of her time per week.

Having the Tumor Registry associated with the Medical Records Department makes the records readily accessible to the Tumor Registry secretary. However, objections have been raised to this organizational arrangement, on the grounds that the typical Medical Records Department is overworked and understaffed and Tumor Registry activities tend to be given less attention than most other activities of the department. As an alternative, the ACS has suggested that either a Tumor Registry secretary or some medical secretary might more appropriately operate a Tumor Registry attached to the Department of Surgery. This aspect of the problem of staffing Tumor Registries was not examined during this study.

It appears that a Medical Records Librarian can learn fairly rapidly how to establish and to supervise a Tumor Registry. Furthermore, such persons usually could arrange their work so that they could attend a 2-4 day training program somewhere within the state, if that be desirable. However, it is doubtful whether most records librarians would have the time to actually code and abstract Registry records if this had to be done in accordance with the complicated End Result Group procedure. If procedures were simpler, such as those now used for the Info-Dex system, many records librarians could completely handle the Tumor Registry if new cases occurred at the rate of no more than 1-2 per day.

Availability of Tumor Registry Secretaries

Where possible, existing Tumor Registries have assigned a person full-time to operate the Registry. The job of this Tumor Registry Secretary is to select, abstract, code, and follow-up cases; to maintain Registry files; and to prepare special reports as requested by the hospital staff. Many Tumor Registry Secretaries were once medical secretaries or associated in some manner with the Medical Records Department. Rarely, however, do Tumor Registry secretaries have the medical educational background of a Medical Records Librarian. At best, they may have taken a one-year correspondence course in record keeping.

The typical Tumor Registry secretary is a woman with a family, who does not wish to leave her home for any long period to train for the position. It thus does not appear feasible to establish a central training program to which potential Tumor Registry secretaries from around the state would be sent for extensive training. Rather, some sort of self-instructional package should be developed and sent out to the local hospitals. Most local hospitals contacted indicated that in all probability time could be provided during the work day for the study of a self-instructional package.

Many people who apply for work in a Tumor Registry Center or a Medical Records Library do not have enough knowledge of medical vocabulary to perform necessary duties. One of the training needs most often expressed to the researchers during the study was for a training package in medical vocabulary which could be used by Tumor Registry secretaries and by the Medical Library Department. Also, it was pointed out that the medical language of diagnosis and treatment constantly changes and some means should be found of keeping both Tumor Registry and Records Department personnel updated with respect to medical treatments and new terminology assoicated with them. Such a training endeavor could be considered by itself, apart from any other development associated with Tumor Registry systems.

Utilization of Tumor Registries

At each hospital visited where there was an ongoing Tumor Registry, the utilization of the information contained in that registry was discussed. This utilization varied widely. Hospitals such as Charity Hospital (New Orleans), request special reports dealing with the adequacy of various types of treatment, and information which can be used as part of the various training programs. There seemed to be an indication that hospitals which were staffed by Tulane or LUS graduates were aware of and interested in using Tumor Registry data. On the other hand, those hospitals which do not have an intern program, or do not have the facilities or staff for handling a wide variety of tumor cases, seemed much less interested in utilizing Tumor Registry results.

Within recent years there has been an increase in interest in the state of Louisiana regarding the development of Tumor Registries. According to Mrs. Wogan, nine hospitals are ready to establish Tumor Registries. Thirteen additional hospitals have requested information regarding Tumor Registries but have not as yet indicated an interest in establishing such a registry. A 1963 survey of Louisiana hospitals

indicated that, of those hospitals which did respond to survey questionnaires, approximately 65% were not interested in the establishment of a Tumor Registry.

It is inevitable that some hospitals will not be interested in Registries. Furthermore, without a concerted effort to educate hospital administration and staff members in the advantages of registry information, the Tumor Registry system will not succeed to any great extent. There is reason to believe that hospital staffs would be interested in having some means of evaluating their own diagnostic and treatment procedures in relation to the rest of the state, but are dubious regarding the cost of such a service.

Information systems often tend to be one-way in nature, and a state-wide Tumor Registry system would have to demonstrate to participating hospitals that the services provided would more than compensate for whatever local effort and expense would be required to gather input data. It might well be appropriate to begin a state-wide system on a rather modest level, tying together a few of the major hospitals in each of the major population areas within the state as an initial step.

Section IV

THE OBJECTIVES, SERVICES, AND PROCEDURES FOR A STATE-WIDE TUMOR REGISTRY SYSTEM

In the opening section of this report, it was noted that a Tumor Registry Planning Subcommittee for the state of Louisiana has been appointed and will be developing information pertaining to the objectives, services, and procedures which should be followed by a Tumor Registry System within the state of Louisiana. During the collection of the information for this report, the HumRRO researchers held numerous discussions regarding these topics with persons having varied types of involvement in the registry problem. In addition, during the preparation of this report we had many occasions to wonder just what should be the objectives of and the nature of a state-wide Tumor Registry system. This section of the report will present some views on these topics.

What should be the objectives of a Tumor Registry System?

What information should it collect? What services should it provide? An article by Abraham Ringle, entitled "The Purpose and Value of a Hospital Cancer Registry", describes three types of Cancer Registries in the United States:

1. A special purpose registry which has a limited scope and is focused on one form or aspect of cancer. The primary purpose of such a registry is education and reference.

2. The epidemiological registry which is concerned with gathering information about the prevalence and incidence of various sites and types of cancer, as well as a variety of research information which can be obtained only from a large volume of data. Ringle points out

that there is no great need for a large number of such registries and that their cost of operation and maintenance is high. The CCNSC End Results Program is concerned with this type of registry.

3. The "hospital evaluatory cancer registry", is the type supported by the American College of Surgeons and the American Cancer Society. Such a registry measures the quantity and quality of medical care provided for cancer patients at a given institution, and supposedly is simple enough in operation to be supported by even the smaller community hospitals. It is suggested that "a properly trained cancer registry secretary should have little difficulty in maintaining and operating a registry, provided she has the continuing assistance and guidance of a position supervisor and the cooperation of the medical staff."

The hospital evaluation cancer registry as described by Dr. Ringle probably is the easiest type of registry to implement throughout a state hospital system. The question is whether such a registry can provide all the data needed by both the local hospital and a state-wide system. It would seem worthwhile to examine the information now collected in smaller Tumor Registries to see whether they do indeed meet the requirements of the local physicians. If so, then there would seem to be a strong argument for choosing this type of fairly simple-to-operate registry to be implemented throughout a state. The centralized portion of the state's system might consist of a data processing capability which could collect and perform appropriate manipulations on any desired mix of Tumor Registry data. Of course, even with relatively simple Tumor Registries, it still would be necessary to devise a means for training large numbers of persons to master the vocabulary, the file keeping, and the record handling required of Tumor Registry personnel.

To what degree should a state-wide Tumor Registry system be centralized?

Centralization of all or portions of a state-wide Tumor Registry system must be considered in terms of the abstracting/coding procedures to be used by the system, and in terms of the services which are to be provided by the system. The following topics need to be taken into account:

1. Abstractor/coder reliability
2. Training problems
3. Ease of recruiting Tumor Registry personnel
4. Desire to simplify operations at the local hospital
5. The maintenance of Tumor Registry interest at the local hospital
6. Local reluctance to release medical records to a central agency
7. Record copying and record mailing costs which could be associated with a centralized system.

The need for some form of Tumor Registry centralization would seem to be in direct proportion to the complexity of the abstracting and

coding procedures required. Adoption of the Charity Hospital (New Orleans) or End Results Group abstracting/coding procedures on a statewide basis would almost assuredly necessitate the centralization of the abstracting and coding process. Adoption of sophisticated abstracting and coding procedures would:

1. Lead to increased staffing problems at the local level, since in many hospitals an additional job position would probably have to be established in order to carry out the Tumor Registry activities.

2. Increase training problems at the local level, in that someone such as a medical record librarian, plus a Tumor Registry secretary, would have to receive a substantial amount of training before they could successfully perform the abstracting and coding procedures.

3. Lower abstractor/coder reliability to a point where a constant check would need to be made concerning the extent to which the records are being reliably abstracted and coded.

4. Possibly increase the amount of work required at the local level because of the need for copying certain portions of the records and sending them to a central abstracting/coding agency.

5. Possibly lead to some resistance at the local level due to a reluctance to forward medical records to a state agency.

6. Possibly lead to less interest in the Tumor Registry at the local level because the local staff would be less involved in Tumor Registry operations.

7. Possibly increase the cost of the total system due to the necessity for having to copy and to transport portions of the record to a central agency.

It would seem that it should be possible to devise a fairly simple abstracting and coding procedure which, although much more gross than those used by either Charity Hospital or the End Result Program, would to some extent be compatible with these more sophisticated procedures. Whereas the Charity Hospital's coding system requires that information be coded in one of six to ten categories, it should be possible to devise a grosser version whereby information would be coded in two or three categories. This would create the possibility of coding information in gross terms and then as desired, returning to selected records and recoding the information in a more refined manner. The simplified coding procedures could be implemented at the community hospital level and if desired, one or more of the major hospitals within the state could employ the complex procedures of the End Result Group.

Adoption of a simplified abstractor/coder procedure for Tumor Registries would make it much more feasible for each participating hospital to have an almost completely self-contained Tumor Registry. Such a self-contained registry should circumvent many of the disadvantages of a registry using more complicated procedures. On the other hand, a completely decentralized registry system would have a lesser capability for preparing reports regarding its own activities and would have practically no capability for comparing its activities to other hospitals and/or population areas within the state.

It would seem advantageous to explore the feasibility of establishing community Tumor Registry Centers which at a minimum would have the responsibility of collecting and processing data provided by local participating hospitals. In addition, these community data centers could take on the responsibility for preparing whatever reports were desired of local hospitals.

If it were decided to adopt the more complex type of abstracting/coding procedures for state-wide procedures, then the community Tumor Registry agency might assume the burden of abstracting and coding the records. Contact teams from this community agency could periodically visit local hospitals to abstract and to code those cases selected by local hospital personnel. As an alternative, on a periodic basis, copies of portions of the selected record could be brought into the community agency for processing.

Section V

ALTERNATIVE TUMOR REGISTRY SYSTEMS

A service-oriented Tumor Registry should have the capability to provide physicians with access to certain information about disease patterns in their practice area and in their hospital admissions. In addition, for each patient a record should be provided of his course through diagnosis and treatment, rehabilitation and follow up. The Registry should be patient-oriented in that it should collect a wide variety of information on all tumor diagnosed cases, and should be capable of rapidly providing a wide variety of reports.

The objectives and services which a Registry should provide should be considered prior to, and separately from, what system should be established to provide them. There are alternative systems for establishing a system of state-wide and national Tumor Registries. For simple Tumor Registries, such as those which now employ the Info-Dex system, it is feasible to have completely parallel facilities at each hospital. As the system becomes more complex and the services required of a Registry become more sophisticated, it becomes less and less feasible to provide each hospital with its own complete facility. Each of the major activities in a Tumor Registry can be analyzed in terms of who should perform it and where it should be performed. From such an analysis one can derive alternative job and organizational structures, each of which should be able to meet the objectives of a Tumor Registry system. Hopefully, one of the alternatives will be appropriate for implementation within any particular state.

Major Activities of a Tumor Registry

In a large Tumor Registry a variety of major types of activities occur. These include: (a) selection of cases for incorporation into the Registry; (b) abstracting of medical records; (c) coding, for data processing purposes, of medical record abstracts; (d) initiation of follow up actions for all active cases within the Registry; (e) incorporation of follow up information into Registry records; (f) preparation of reports;

(g) maintenance of the Registry files; (h) as required, training of new Registry personnel; (i) supervision of Registry personnel and operations. Alternative procedures for accomplishing these activities will be briefly described below.

Selection of Records for Incorporation into Registry Files

1. By the Medical Records Department. Typically a Tumor Registry is attached to the Medical Records Department. As the patient's records are processed by this department, those which deal with diseases of interest to the Registry are selected by the Medical Records personnel for further processing by a Tumor Registry secretary. This procedure is easy to implement; however, experience has shown that, if it is followed, a fair number of records that ought to be incorporated into the Tumor Registry are in fact not selected.

2. By Tumor Registry secretary. In a hospital where the Tumor Registry is attached to the Medical Records Library, it might be possible for the Tumor Registry secretary to screen all records as they come to the Medical Record Department. This should increase the likelihood that those records which ought to be incorporated into the Registry are indeed selected for incorporation. To our knowledge this selection procedure is not currently employed within the state of Louisiana.

3. By the attending physician. To implement this procedure, hospitals would have to be provided with a list of reportable tumor conditions. Cases meeting these reporting conditions (confirmed or suspected) could be immediately reported to the Tumor Registry and the medical record tagged for eventual processing by the Tumor Registry. This procedure would seem to have considerable merit since the physician is most capable of determining whether the medical case deals with a tumorous condition.

4. By Tumor Registry personnel. In some hospitals, Tumor Registry personnel screen the records and reports emanating from such labs as pathology, cytology, and radiology, and they also attend Tumor Committee Conferences. By these means, TR personnel obtain information regarding those cases which should eventually show up as candidates for incorporation into the Registry.

Abstracting of Medical Records

1. By the attending physician, supplemented by the Tumor Registry secretary. It would seem most desirable to devise a form that the physician would use to abstract and record items of information important to the Tumor Registry -- specifically, items that require the exercise of medical judgment. The Tumor Registry secretary would abstract from the records those other informational items requiring little or no medical judgment. A procedure akin to this is now being used by the U.S. Public Health Service Hospital in New Orleans.

2. By the Tumor Registry secretary, supplemented by a physician. Some variant of this procedure is employed at most Tumor Registries. Typically, the records are completely abstracted by a Tumor Registry secretary, with a medical consultant assisting in the abstracting and coding when needed; in difficult cases the attending physician may be contacted.

This is a less desirable procedure than that described in No. 1 above because the Tumor Registry secretary must make medical judgments in cases where even medical experts might not be in agreement.

3. By an abstracting Contact Team. It would be possible to establish--at either community, regional, or state-wide level--abstracting teams that would periodically visit each hospital and abstract those cases selected for incorporation into the Registry system. The use of Contact Teams should be particularly advantageous for providing an abstracting capability to smaller hospitals.

4. By a centrally located abstracting facility. Portions of medical records could be copied by the local Tumor Registry secretary and sent to a community or state agency that would perform the actual abstracting. This alternative would have advantages similar to those of the Contact Team alternative, in that a cadre of highly trained abstractors would provide this service for all hospitals within the state. It should be noted that the problems associated with copying and transporting medical records would have to be thoroughly explored to ascertain the feasibility of this approach.

Coding of Medical Record Abstracts

The abstracting and coding processes ordinarily are best carried out by the same person. When the same person performs both steps, the abstract is more likely to contain all of the information that will be needed during coding. However, having the abstracting and coding activities performed by different persons may well be efficient if a means can be found to collect abstracted information that will meet the requirements of the record coder. This might be achieved through the use of a well-designed abstract form; this point will be discussed more fully later on in this report.

Alternative coding procedures are:

1. By the attending physician. This alternative can hardly be given serious consideration, since the time required would impinge on other obligations of the physician, and since the activity can be successfully performed by medical technicians.

2. By Tumor Registry secretaries, supplemented by a physician consultant. This is the procedure currently employed at most Tumor Registries. It is successful to the degree that an adequate abstract, containing all the information needed during the coding process, can be provided; utilizing End Result Group procedures for coding requires a high degree of training before the complicated set of instructions can be followed reliably. This alternative can be successfully implemented if (a) means can be found by which the attending physician can provide an adequate abstract of the record; (b) reference material for abstractor/coders can be improved so as to make it easier to follow; and (c) suitable abstractor/coder training programs can be developed.

3. By Contact Teams. We suggested above that contact teams could be used to abstract medical records. If this procedure were to be followed, the same teams could code the material which they abstract and could be responsible for transporting the data back to a central

data processing facility. This alternative has a major advantage in that the same person could both abstract and code a record.

4. By a central community-wide or state-wide coding facility. Assuming that acceptable procedures and forms can be devised for abstracting tumor cases, copies of this information could be forwarded to a central facility responsible for coding, and for data processing of this information.

Initiation of Follow-Up Actions for all Cases Active Within Registry

1. By a Tumor Registry secretary at the local hospital. This activity can be performed readily by the local Tumor Registry secretary. Procedures would have to be worked out for incorporating follow-up information into the Tumor Registry Data Bank. These procedures should be patterned on those used for the abstracting and coding of the original records.

2. By a central community-wide or state-wide registry facility. While it would be feasible for follow-up actions to be initiated by a central facility, this seems less efficient than alternative No. 1 above. Each Tumor Registry should contain at least one full-time job position, and at the smaller registries inclusion of follow-up activities would help ensure that the Tumor Registry secretary could be employed full-time on registry activities. In addition, it would seem advantageous to have follow-up information first available to that local hospital most apt to be interested. Arrangements could be made between the local physician and the Tumor Registry secretary to pass on immediately certain items of interest.

Maintenance of Registry Files

In a state-wide computerized Tumor Registry system, there are a number of alternative ways in which Registry records can be stored, retrieved, and made available as needed. Presumably any local Tumor Registry would wish to have its own set of files to ensure access at any time. A Tumor Registry secretary should have no difficulty maintaining such files.

In the future, a state-wide Registry system might be tied together by a sophisticated computer system employing remote input-output devices. Local users could readily contact their own files within the central system and on their output devices could make hard copies of portions of their file. With such a system, the local Tumor Registry secretary could still have the responsibility for maintaining and operating the files for her Registry.

Preparation of Reports

Tumor Registries must be service-oriented; they must be able to provide a wide variety of data and reports quickly upon request. It can be presumed that physicians at a local hospital will want information regarding their own patients, and also information regarding what is going on within their own hospital and immediate community as compared with either or both state-wide and national conditions. A second set of

users might be most interested in reports comparing and describing state-wide conditions. A third group of users, the End Result Group, would be interested in obtaining data which could be used for national comparative purposes. The information requirements of all important users must be considered when establishing a Tumor Registry system, to include the procedures by which these users are to be provided with data and reports.

1. By Tumor Registry secretaries. At Charity Hospital (New Orleans), Tumor Registry personnel have the capability of preparing year-end summary reports, and reports that can be used for teaching purposes. At a local hospital a Tumor Registry secretary should be able to prepare some reports, but it is doubtful whether she should be required to do much of this. Preferably, it should be her job to take requests of the local physicians and to cast them in such form that they can be answered quickly by a central data processing facility.

2. By a central data processing facility. A central facility would be best equipped to provide reports and data of national or state-wide significance. It should be the function of such a facility to collect information and to pass it on to such agencies as the End Result Group or interested committees of the Louisiana State Medical Society. However, care should be taken to ensure that such a central facility does not cater to state-wide and national users to the detriment of community and local hospital requirements. Above all, to be patient-oriented a state-wide reporting facility should be capable of and oriented to answering those questions which originate at the local hospital. Only in this way can the system demonstrate to the practicing physician that his effort to support the system is worthwhile.

Upgrading and/or Establishment of Tumor Registries

Essentially this can be done by one of two procedures, by contact teams or by training a Tumor Registry secretary who will then establish the registry. Both procedures are employed within Louisiana.

1. By Contact Teams. Currently Mrs. Marion Wogan, Louisiana State Medical Society Hospital Tumor Registry Consultant, visits hospitals within the state and instructs the medical records librarian regarding the procedures for establishing and operating a Tumor Registry. This procedure seems to have met with some success. It could be improved by having contact teams with several members, who would visit Tumor Registries periodically to assure that their activation or upgrading was proceeding on course.

2. By Tumor Registry secretaries. Discussions with medical records librarians suggested that these persons could attend a centrally located two- to four-day training session which would be devoted to instructing them in the procedures for establishing a registry. Assuming that these persons were then provided with suitable printed instructions and registry paraphernalia, they should be able to initiate a Tumor Registry. This should be preceded by some sort of interaction with both key hospital administrator personnel and surgery department personnel, to apprise them of the objectives of the Tumor Registry and solicit their aid in establishing such a Registry.

Section VI

RELATION BETWEEN TUMOR REGISTRY PROCEDURAL ALTERNATIVES AND EXTENT OF PHYSICIAN INVOLVEMENT IN RECORD ABSTRACTING

The procedures to be adopted for the selection, abstracting, and coding of tumor records are highly dependent upon the extent to which physicians can be involved in record selection and abstraction. Problems concerning the selection of records could be greatly alleviated if it were a requirement that the attending physician report these cases to the Tumor Registry and see that the medical record is tagged for processing by the Tumor Registry.

The processes of abstracting and coding a medical record are highly dependent upon the degree to which adequate medical records are maintained by the attending physician, and by the degree to which an acceptable abstract can be provided to the person who is to code the record. Many of the abstracting and coding problems of a registry could be lessened by developing a series of forms physicians could use to record their diagnostic and treatment actions more precisely. In addition, it would seem highly desirable to develop an abstract form the physician could use to summarize pertinent information in the medical record. If the above procedures could be implemented, it would seem quite feasible to have the remainder of the record abstracting, and possibly even all of the record coding, performed by a Tumor Registry secretary at the local hospital.

It seems very clear that, for best results, the attending physician -- to the maximum extent possible -- should be assigned the task of abstracting the tumor records, in the sense of recording essential medical information that he already has. Furthermore, we feel that abstracting can be greatly improved by the development of better medical record forms, designed for use by the physician and for subsequent registry needs.

Section VII

TRAINING IMPLICATIONS OF A STATE-WIDE TUMOR REGISTRY SYSTEM

Need for Better Job Aids and Reference Material

Tumor Registry personnel perform six major types of activities. These are:

1. The selection of records for incorporation into the registry
2. Abstracting medical records
3. Coding, for data processing purposes, the medical record abstract
4. Initiating follow-up actions for all cases within the registry
5. Maintenance of the tumor registry files
6. Preparation of reports

To these six activities can be added those concerning the activation of a registry and the supervision of registry personnel and operations.

For each of the above eight activities, there do exist various types of guidance and reference materials that can be used by Tumor Registry personnel. However, no formal training programs exist for any of these activities, and with rare exceptions the printed material and the reference material are not definitive. This is especially evident in the two difficult areas of abstracting and coding; the CCNSC End Results Group and the Charity Hospital Tumor Registry have prepared job aids which are quite detailed in these two areas but even these job aids cannot be used proficiently without extensive on-the-job experience. The activities of an abstractor/coder can be simplified by the development of well-organized and informative reference materials and job aids. Our review of the existing references and job aids led us to believe that there is room for much improvement in these materials. Such improvement would lessen training problems and in all probability would increase the reliability of the abstractor/coder.

A high priority should be given to the improvement of those job aids now used in Tumor Registries. No matter what job positions and training packages eventually are developed when objectives for a state-wide TR system have been established, development of materials of this sort will be essential to successful implementation.

Need for Training Tumor Registry Secretaries

Descriptive material does exist which quite adequately describes the filing and similar routine procedures associated with the conduct of a Tumor Registry. The need for additional material covering these procedures does not appear to be too great.

Need for Training of Abstractors and Coders

The two most difficult Tumor Registry training problems concern the abstracting and coding of medical records. While coding might not be involved, in a simpler TR system it may be that all Registries should code their abstracts. For example, at the Charity Hospital, New Orleans Registry the same person both abstracts and codes the case material -- an efficient arrangement because the person who abstracts a record must be sure to provide all of the material that will be needed to make the decisions during the coding process. In effect, the requirements of the coding procedure determine what material should be included in the abstract. To insure a standardized abstract content, it may well be necessary to superimpose coding rules on this abstracting process so as to provide abstracting guidelines.

In a small Tumor Registry the Tumor Registry secretary would have to be trained to abstract and to code the records. There is no training material that can be used to teach these two activities, and development of some type of formal training procedures for coders and abstractors is definitely needed. As indicated previously, the nature of this training depends upon the procedures which are to be used by the Registry centers, and the number of Registry center personnel who must

be employed.

The development of self-instructional material is an expensive undertaking; it can best be justified by demonstrating that it could be used to train large numbers of people. If only a small number of people are to be trained, then one has to consider the establishment of the more traditional type of classroom instructional program which might be taught at various times during the year by the personnel of an existing large Tumor Registry Center. Using this approach, instructional procedures, lecture material, demonstration material, and so forth would have to be prepared, but the expense of this would very probably be less than for the development and try-out of a self-instructional package.

For the teaching of fairly simple coding and abstracting procedures, it seems feasible to develop a complete self-instructional package. For the teaching of complex coding and operating procedures, it seems most feasible to use a dual approach. That is, a self-instructional package could be developed to prepare a person for an intensive lecture and on-the-job training program lasting two or three weeks, with students being brought into a large registry and given formal instructions and close supervision while they practice the intricate details of coding and abstracting. By this dual approach the students could be prepared at home so that they could maximally profit from the tutorial instruction which they could receive at a large registry. Such a self-instructional package would not attempt to teach all of the details of coding and abstracting, so development would be less difficult. If desired, a follow-up set of self-instructional material could be developed to be administered in the fashion of a correspondence course.

No matter what abstracting/coding procedures are finally adopted for a state-wide system, it would seem desirable to develop a self-study training package for the bulk of these procedures. This is especially applicable if the procedures are to be followed by Tumor Registry secretaries at the local hospital.

With respect to nation-wide goals, it still might be advantageous to consider the development of self-study training packages which teach the procedures advocated by the CCNSC End Result Group. If this package were to be sent only to larger hospitals which might participate in the End Result Program, it would then be permissible to make certain assumptions about the qualifications of the personnel within these larger hospitals who would be assigned to work in a Tumor Registry Center. For example, one might assume that personnel could be selected who were already familiar with medical terminology. This would ease the training problem.

Training Users of Tumor Registries

Most of us are familiar with some instructional material prepared by service departments within our own organization -- for example, a technical library may publish material to educate its users in making the most of the library's resources. The preparation of this type of training material is not especially difficult, but it contributes greatly to the support and continuation of the service activity.

The purpose of tumor registries is to provide services, and such registries will succeed to the extent that they are service-oriented. However, registries must also actively engage in "selling" their services. That is, they must educate potential users in the advantages that can be gained from actively using the information within the registry. In this way the local hospitals are most apt to maintain their interest in the active support of the registry. It would seem appropriate to develop brochures which would inform hospital staffs of the benefits from using and supporting a state-wide Tumor Registry system. Coupled with this should be information on what services are provided by the Registry and how to obtain these services.

Medical Vocabulary Training

Operating a Tumor Registry requires personnel who are familiar with medical records and with medical terminology. Obviously this suggests that people from the Medical Records Department are the most likely candidates for Tumor Registry work, but then the question merely becomes one of where the people come from who work in the Medical Record Department. It would seem that it would be useful to provide some type of formal training in the areas of medical terminology and the composition of medical records. Many persons when first employed in a Medical Records Department or in a Tumor Registry are not familiar with the medical terminology which they encounter. During our consulting activities, numerous persons mentioned the time and the effort which it takes to teach someone an appropriate medical vocabulary. This is an area which is very suitable for teaching by self-instructional techniques. It would seem quite feasible to develop a self-instructional training package which would teach the vocabulary required by Medical Records Department and/or Tumor Registry personnel.

Section VIII

OTHER RESEARCH PROJECTS RELATING TO TUMOR REGISTRIES

Hospital Staff Information Requirements

In considering the establishment of a state-wide Tumor Registry system, much thought needs to be given to the types of information to be collected by this system and the services it should provide. The development of such a system should begin with analysis of the information requirements of the users it will serve.

The many articles which have been written about Tumor Registries and the many forms which have been developed for use by Tumor Registries all assume that it is important to collect certain types of information and to have the capability of providing certain types of information and certain types of reports to members of the hospital staff. There still, however, appears to be some question regarding the exact types of information and services which a registry should provide. A research study in this area should be given serious consideration.

Abstractor-Coder Reliability

There is a very close relationship between the processes of abstracting and coding, and we have noted that it is the coding procedures which provide the structure for and dictate the content of the abstract. Even when a fairly simple abstracting procedure, such as that recommended by the American College of Surgeons, is being used, there is no clear evidence regarding the degree to which two equally capable abstractors will abstract the same record in a similar fashion. In other words, even with a simple system the reliability of the data is unknown.

There is a need to conduct research concerning the degree to which Tumor Registry personnel can reliably abstract and code medical records. Such research should include the development of simplified abstracting and coding procedures. It seems probable that simplified procedures can be devised which can be readily taught and reliably utilized by Tumor Registry personnel at smaller hospitals. This research might include the development of procedures for assessing abstracting-coding reliability.

Feasibility of Centralized Coding

It may be possible, if fairly simple types of coding are required, to develop abstracting procedures such that local tumor registry personnel could abstract a case and then pass this case on to a centralized group for coding. The degree to which this is feasible is unknown and this is a suitable project for research. If it is possible to have different people abstract and code, then at the community level there could be persons who code all cases within the community and prepare reports for hospitals within the community. In addition, this community agency would be responsible for passing data on to any existing state agency.

Tumor Registry Systems Research

Using operation research techniques, and perhaps simulation techniques, it should be possible to develop fairly adequate estimates regarding the probable cost and practicability of alternative Tumor Registry systems.

ADDENDUM

RECENT DEVELOPMENTS

On 5 August 1968, representatives of the American College of Surgeons, American Cancer Society, Regional Medical Program, End Results Group, and many other medical groups met at the National Institutes of Health, Bethesda, Maryland. At this meeting a regional medical program position paper on registries was presented which proposed the establishment of service-oriented Tumor Registries throughout the nation. (The DRMP position paper on registries is attached as Appendix A.)

Included in this proposal was a tentative list of information items which should be collected by each Registry for each cancer record. These items of information are similar to those now collected by registries which feed their data into the End Results Program of NIH. Under the DRMP proposal, abstracted data from local Tumor Registries would be fed into a central data-processing agency, which would have the capability of providing a variety of reports to the local hospital.

At the 5 August 1968 meeting, the DRMP position paper was accepted in principle. On this same date, at an associated meeting of the American College of Surgeons, a position was adopted that hospitals should have a Tumor Registry as a service function and not as a mere disease list.

The above decisions may mean that in the future hospitals which wish to perform cancer operations will have to have an approved Tumor Registry. This would mean that from eight to ten thousand registries would have to be established, and personnel found and trained to staff these registries. Obviously this would have far-reaching manpower and training implications.

It is extremely important to note that while a decision has been made to emphasize the establishment of Tumor Registries, it is not presumed that these registries will be tied into the NIH End Results Group Program. The registries will collect information somewhat similar to those registries now a part of the ERG program; however, as yet no decision has been made to require that this information be coded using ERG coding procedures. Indeed, it may be that at these new registries no coding procedures will be required. The importance of this possibility is this: the abstracting of medical records is a reasonably straightforward process, which can be learned in a reasonable length of time, and performed quite rapidly. On the other hand, the coding of medical records, especially in accordance with ERG coding procedures, is a very difficult and time-consuming task, and could not be readily taught to large numbers of people. In short, the decisions mentioned above should simplify the establishment and operation of Tumor Registries -- if at these registries Tumor records will be selected and abstracted, <u>but not coded</u>.

The findings and discussions in the body of this report must now be interpreted in terms of the abstracting and the coding procedures which eventually might be required of Tumor Registries:

1. If newly established Tumor Registries are required only to abstract records in accordance with ERG-like information requirements, then it can be concluded that: (a) It is feasible to train large numbers of persons to select, abstract, and perform the other operational requirements of a Tumor Registry. (b) It does seem feasible to establish fairly complete registries at each hospital, and in all probability the medical record librarian could take on the overall supervision of the Registry. (c) In training Tumor Registry personnel, the most difficult training problem would be one of teaching a Tumor Registry secretary an appropriate medical vocabulary. (d) It would appear that the development of a medical vocabulary training program can commence immediately.

2. If it is eventually decided to establish Tumor Registries which will both abstract and code tumor cases in accordance with the ERG-like procedures, then it can be concluded that: (a) It is premature to attempt to develop specific training programs for Tumor Registry supervisors and/or abstractor-coders until the nature of the proposed state-wide and/or national Tumor Registry system has been more clearly defined. (b) There would be a need to conduct a wide variety of systems-research designed to provide the data required to decide on a suitable configuration for the Tumor Registry system. Among other things, this research should determine the degree to which the coding of medical abstracts can be performed by either contact teams or by a central abstracting agency. (c) It is extremely doubtful whether it would be feasible to train large numbers of Tumor Registry secretaries to reliably code tumor cases on the basis of ERG-like coding procedures.

Based on the assumption that new Tumor Registries will abstract but not code medical records, it would seem reasonable to undertake, in the near future, the following projects: (a) the development of a medical vocabulary self-instructional package which could be used to teach Tumor Registry vocabulary; (b) the development of material which could be used to familiarize hospital administrators and staff physicians regarding the activities of and the services which can be provided by Tumor Registries, and a Tumor Registry state-wide system.

After the characteristics of a state-wide Tumor Registry system for the state of Louisiana have been defined in greater detail, it would seem appropriate to conduct the following types of training projects:

1. The development of either a self-instructional package or a 2-4 day training program which could be used to teach medical records librarians the procedures for establishing and operating a Tumor Registry.

2. The development of a self-instructional training package for teaching Tumor Registry secretaries how to select and to abstract medical records dealing with tumors.

3. The investigation of the need for job-aids and reference materials which can be used by Tumor Registry personnel during the process of selecting and abstracting medical records. This effort should include the development of job aids and reference materials as deemed appropriate.

4. The development of quality control procedures by which a periodic evaluation could be made of the record selection and record abstracting capabilities of a Tumor Registry secretary.

5. The development of information dissemination procedures by which knowledge regarding new tumor diagnostic and treatment procedures and their associated medical terminology could be made available to all Tumor Registry personnel. This would be considered part of a continuing education system for Registry personnel.

In addition to training-oriented and performance-oriented research, the following types of system-research should be considered:

1. A "user" study designed to determine who the users of a Tumor Registry system would be and what types of questions and reports might be requested by these users. Such information could be used to determine the capabilities which should be possessed by a Registry central data-processing facility.

2. An investigation of the degree to which certain portions of existing medical records could be redesigned and/or standardized so as to make it easier to abstract the record. This research should include the development of a Tumor abstract form which could be completed, at least in part, by the attending physician.

3. An examination of the report preparation capability which should be possessed by a local registry. Theoretically, a central data-processing facility would have the capability of providing all needed reports. However, it would be useful to examine the degree to which certain types of records should be maintained at the local registry so as to have them immediately available to the hospital staff.

APPENDIX A

DRMP POSITION PAPER ON REGISTRIES

At the February meeting of the NAC-RMP, Dr. Marston promised that the staff would review all statements made by the Council members in previous discussions of registries, obtain advice from experts in the registry field, and develop a DRMP position paper on the subject for submission to the May Council.

The DRMP staff has conducted a review of the following:

1) Statements on Registries by the DRMP Review Committee.

2) Statements on Registries by the DRMP National Advisory Council.

3) Seminar on Data Collection and Registries held by the DRMP at Linden Hill Hotel on March 16, 1967.
See Appendix I.

4) Conference on Data Gathering Functions under PL 89-239 and PL 89-749, held by the DRMP at NIH, on May 15, 1967.
See Appendix II.

5) Symposium on Registries held by American Association for Cancer Education in Saratoga Springs, New York, on October 15-17, 1967.

6) Cancer Registry Consultants Meeting held by the Georgia Regional Medical Program in Atlanta, December 8, 1967.
See Appendix III.

7) Document on "Stroke Registries" prepared for the DRMP by the Joint Council Subcommittee on Cerebrovascular Disease.
See Appendix IV.

8) Announcement of Cancer Registry Form from Commission on Professional and Hospital Activities.
See Appendix V.

9) Statement regarding Intermountain Cancer Registry.

In addition, the staff has consulted with registry experts of the following:

a) National Cancer Institute
b) National Heart Institute
c) National Center for Chronic Disease Control
d) Joint Council Subcommittee on Cerebrovascular Disease
e) Commission on Professional and Hospital Activities
f) American Cancer Society
g) American College of Surgeons

DRMP Position Paper on Registries

The following is a statement prepared by the DRMP staff summarizing the opinions we have been able to gather together, and relating them to the needs of Regional Medical Programs.

Registries (chiefly for cancer) have gained a bad name among many physicians in this country, yet the DRMP continues to receive applications for the support of cancer registries, representing a major part of the cancer activities of a number of RMPs, activities to which the regional planning staffs and the Regional Advisory Groups attach a high priority. The Review Committee and the Council will continue to debate the pros and cons of each application--much of it the same debate with the expression of the same opinions--unless we can develop criteria which can specify what kinds of registries are good for RMPs and what kinds are worthless, and what elements should be included to insure that the welfare of patients will really be improved by the support of a registry. Also, we must learn what has gone wrong with many registries in the past.

Registries have been established for a variety of purposes: 1) epidemiologic research; 2) assessing the incidence of various types of cancer (in areas where an entire population is covered); 3) determining trends in incidence and results of treatment in different types of cancer over the years; 4) determining admissions for different types of cancer, in a given hospital; 5) evaluating the end results of treatment on a research basis; and 6) sometimes only in order to comply with the American College of Surgeons' standards for accreditation of a hospital cancer clinical activities program. Very few have been organized to return follow-up information to practicing physicians on a regular basis, and, even in hospitals, registry data have rarely been adequatley utilized by the staff either for medical audit and education or for actual patient follow-up.

The dismal failures of many registries can be traced to such factors as:

1) Lack of leadership. A successful registry needs to be supervised by someone, preferably a physician, who not only knows how a registry should be run, but also believes in its value, who can communicate his enthusiasm and interest to the hospital and registry staffs, who will encourage the physicians to prepare complete and legible patient records and the registry staff to abstract the data carefully and accurately, and who will arrange teaching conferences for house staff and attending physicians utilizing the registry data.

2) Lack of funds to hire sufficient personnel.

3) Inadequate training of personnel.

4) Lack of an effective system for accumulating and handling data.

5) Lack of quality control.

6) Failure to provide useful information to physicians for the follow-up of their patients.

7) Failure on the part of physicians who should be contributing to a registry to complete their patient records conscientiously.

8) Failure of the house staff and physicians associated with the hospital to utilize the registry data adequately for continuing education and evaluation of the treatment of their patients.

If physicians in the United States are to be afforded the opportunity to provide the highest quality of medical care for their patients, they need to have access to certain information about the disease patterns in their practice areas or in their hospital admissions, and--for each patient--a record of his course through diagnosis and treatment, rehabilitation and follow-up. The doctor needs to know the patient's history after the treatment he administers, supervises, or obtains for his patient by referral to a specialist or hospital. He needs to keep in contact with each patient throughout his life, if possible, particularly for patients with cancer, myocardial infarction and stroke, and to assure appropriate follow-up of his condition. And, particularly, he needs to know the end results of his treatment as a guide to the delivery of better treatment to patients in the future. In short, he needs data--of a kind that can be, but often is not, provided by a registry.

Regional Medical Programs, therefore, have special reasons to give serious consideration to the support of patient-oriented registry activities across the nation. The focus of RMPs is on the patient, and patients with heart disease, cancer, and stroke need to be followed if we are to be sure that they receive the best treatment modern medicine can provide.

The cost need not be as exhorbitant as many people have feared. Smaller hospitals can utilize central computerized data processing facilities in larger hospitals or in central or regional registries, or they can purchase data processing services as needed.

Certainly, one worthwhile achievement of RMPs would be the development of better patient records in all hospitals in the country, utilizing as much automation and computerization as possible. It is not difficult to develop a good registry operation based on the record room of any hospital in which the staff and attendings are conscientious in preparing good patient records. It usually requires physician direction, built-in checks for quality control and assurance of the competence of registry personnel. Although the cost of such an operation should be a natural responsibility of each hospital, it would seem an appropriate use of RMP funds to support on a temporary basis the training and salaries of key registry personnel in hospitals in order to stimulate the development of a higher standard of registry activity, with the expectation that, once established, this responsibility would be assumed by the hospitals, with the cost considered a legitimate part of the charges to the patient and his insurance carrier.

RMPs, therefore, afford an unusual opportunity to develop effective service-oriented cancer registries in all parts of the country. The

emphasis on patient follow-up which must be a part of optimum care, and the stimulus to continuing education activities which are an integral part of each RMP, create greater physician awareness of the value of, and need for, good registries. If existing registries can be raised to the level of those now participating in the End Results Program of the National Cancer Institute, if new registries can be developed where indicated, if physicians can be provided with conveniently usable data at reasonable cost, and if they can be supported in the utilization of those data for educational purposes, RMPs will have made a notable contribution to the delivery of better health services to the American people.

The greatest need for such registry activity is, unquestionably, in the field of cancer, because of the danger of recurrence of the original disease and because patients with one form of cancer appear to be more likely to develop a second malignancy than other patients are to develop cancer at all.

The extension of such considerations to myocardial infarction and stroke registries is in progress, but these are at present being supported only on a research and demonstration basis.

Goals and Characteristics

of

R E G I S T R I E S

Qualifying for Support by Regional Medical Programs

Goals:

1. To assist physicians in the follow-up and continuity of care of each diagnosed cancer patient. (Consideration should be given to extension of registry service for patients with heart disease and stroke.)
2. To provide feedback of information to physicians and hospitals for:
   a. Improving patient management, including quality of survival.
   b. Continuing education of the staff through end results analysis.
3. To provide a base for:
   a. Analysis of cancer admissions to each hospital for planning purposes.
   b. Evaluation of treatment by end results analysis, including quality of survival.
   c. If population based:
      (1) Estimate of incidence and prevalence of different types of cancer.
      (2) Estimate of incidence by sex, age, type, and site.
      (3) Analysis of changes in incidence, in stage of disease at diagnosis, in modes of diagnosis and treatment, and in end results of treatment.
      (4) Evaluation of success or failure of cancer control programs under auspices of RMP or other.
      (5) Provision of data on magnitude of cancer problems in region for purposes of planning by RMP and by state and county officials.

Characteristics:

1) Physician direction
2) Adequate staff

   Staff should be adequate in number and training to establish and maintain registry (including access to a biostatistician).

3) Adequate funding

4) Quality control

5) Use of International Classification of Diseases (Adapted) (ICDA) for comparability.

6) Utilization of common computer programming and facilities as much as possible.

7) Provision of confidentiality.

8) Routine feedback to physicians and hospitals.

ITEMS OF INFORMATION FOR CANCER REGISTRIES

* Optional at local and central
** Optional at central registry

A. Identification:

1. Hospital

   a. Name (in abbreviated form or Code number (At central registry, name will be converted to a code number)

** b. Location

2. Patient

   a. Name -- surname, first, middle

* Mrs. (when applicable)

   b. Chart number

* c. Hospital registry accession number

   d. Central registry accession number

* e. Social security number

   f. Address -- street, city, (county), state

** g. Phone number

** h. Relative or other contact
   1) relationship
   2) name, address, phone

* i. Employer -- name, address, phone

B. Demographic Information:

1. Race
2. Sex
3. Date of birth -- month, day, year
4. Marital status -- single, married, widowed, divorced, or separated

* 5. Occupation -- nature of job and industry

* 6. Country of birth - patient, mother, father

C. History:

* 1. Prior cancer (other than epidermoid skin cancer) -- no, yes
If yes: diagnosis, date, treatment

2. Prior diagnosis of this cancer -- no, yes
If yes:

   a. Name of hospital or physician
   b. Diagnosis (site and type) and date

* c. Method of diagnosis -- histology, hematology, cytology, X-ray, clinical only, other (specify)

d. Was treatment given for this neoplasm -- no, yes
If yes: Type of treatment and date(s)

* 3. Delay -- dates of:

a. First symptoms
b. First sought medical advice
c. First diagnosis
d. Initiation of treatment

4. Date admitted to this hospital

* 5. Date of discharge (first)

D. Diagnosis (final):

1. Primary site -- minimum detail as per ICD

2. Histologic type -- detail as per Manual of Tumor Nomenclature, 1968 revision

* 3. Sequence number

* 4. Histopathologic diagnosis

a. Descriptive diagnosis
b. Date
c. Hospital (or laboratory)
d. Slide numbers

5. Extent of disease -- assessment of extent of disease at initiation of treatment based on all information available during first course of treatment

a. Summary classification --
Localized
Regional node involvement
Direct extension to adjacent tissues
Regional nodes plus adjacent tissues
Distant or diffuse spread
Note: A more detailed descriptive scheme may be used, provided it is compatible with the summary classification

* b. Detailed description in text form or via a check list

* 6. Clinical assessment of extent of disease

a. Summary classification per American Joint Committee
b. Detailed description in test form or via a check list

E. Treatment:

1. First course -- in the absence of specific information regarding the planned course of treatment, include all tumor-directed treatment initiated within 4 months of diagnosis. Indicate date of initiation of each type of treatment, i.e., surgery, beam radiation, other radiation, chemotherapy, hormone therapy, endocrine surgery, endocrine radiation.

* 2. Supportive therapy -- only treatment given; or preceding first tumor-directed treatment.

3. Subsequent treatment -- record as per first course of treatment, but for coding purposes it is sufficient to combine all subsequent treatment to identify types given.

* 4. Description of treatments given -- including detailed description of extent of surgery; radiation fields and dosage; specific chemotherapeutic agents, route, and dosage; etc.

F. Follow-up:

1. Date of contact (or death)

** 2. Source of information

3. Vital status -- alive or dead

* 4. Disease status at last contact or death
- No evidence of cancer
- In remission
- Evidence of cancer
  - Residual (never free)
  - Recurrent
  - Cancer present, but origin not known
- Unknown

* 5. Performance status -- at each hospital discharge; at each contact
- Normal activity
  - Asymptomatic
  - Symptomatic
- Unable to work
  - Capable of selfcare
  - Not capable of selfcare
- Severely disabled
  - Not terminal
  - Terminal
- Dead

6. Cause of death

a. Per death certificate

* b. Per best available information; indicate source

7. Survival time -- years and months

** 8. Physician (or clinic) responsible for patient follow-up

* 9. Other interested physician